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ABSTRACT

This study, one in a series of qualitative case studies on state and national practices in deinstitutionalization and community integration of people with disabilities, was conducted in 1991-92 and involved semistructured on-site interviews with administrators in the 12 New Hampshire regions. The focus is on two key milestones in the development of the New Hampshire community service system: first, the concept of area agencies and, second, the use of the home and community-based Medicaid waiver. This case study has three primary sections. First, it briefly presents an overview and analysis of the regional structures, especially the tension that characterizes the relationship between the regions and the state Division of Mental Health and Developmental Services. Next, the study describes application of the home and community-based Medicaid waiver, and contrasts it with intermediate care facilities (ICFs) for people with mental retardation. The third section presents a framework for thinking about regulations. Conclusions include the importance of local control, the need for intermediary structures to provide necessary flexibility, and the flexibility and cost-effectiveness of the Medicaid waiver in moving individuals with disabilities from institutional to community life. An appendix provides more detail about three regions in New Hampshire: Region V, Region VI, and Stafford County. (DB)

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CRITICAL STRUCTURAL FACTORS IN COMMUNITY DEVELOPMENT IN NEW HAMPSHIRE

COMMUNITY AND POLICY STUDIES

EC 303556

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CRITICAL STRUCTURAL FACTORS IN COMMUNITY DEVELOPMENT IN NEW HAMPSHIRE

Julie Ann Racino

COMMUNITY AND POLICY STUDIES
Syracuse, New York

1993/94

This is one in a series of qualitative case studies on state and national practices in deinstitutionalization and community integration and the changes that will be necessary to promote full participation of people with disabilities in all aspects of community life and daily policy making. The research for this study was conducted in Fall 1991 through Summer 1992 in the state of New Hampshire.

The author extends particular thanks to Donald Shumway, Richard Lepore, Richard Crocker, Dan Van Keuren, Doug Watson, Jane Hunt, Sandy Pelletier, Don Trites, David King, Ric Crowley, Dottie Tessier and Jocelyn Gallant. David Merrill of Nebraska, Karan Burnette of Arkansas and Ginny Harmon of Michigan were particularly helpful with their review and commentary on this case study.

> The issue to me that stood out is people working together. Here in New Hampshire, and as I have seen elsewhere, there is a strong potential for fragmenting philosophies and directions and a strong antagonism that can come from that...We had the potential, but it didn't happen.
>
> - Robert Schultz, New Hampshire state administrator

Working together throughout the course of this decade's development of the community services system, New Hampshire has had a remarkable consistency in state administration, regional services, and other parent and advocacy leadership in the area of developmental disabilities. This "enormous consistency" has allowed people to "learn from each other" and to "build trust" in a way that "became a very self regenerating process."

This case study shares the perspectives, primarily of state administrators at the Division of Mental Health and Developmental Services, who have been involved with systems development over 10 years and have played key roles since the time when there were very few community services in the state. As with all retrospective accounts, history is remembered somewhat differently by each person who participates in its making, partially dependent on factors such as their role, personality, and the nature and level of their involvement.

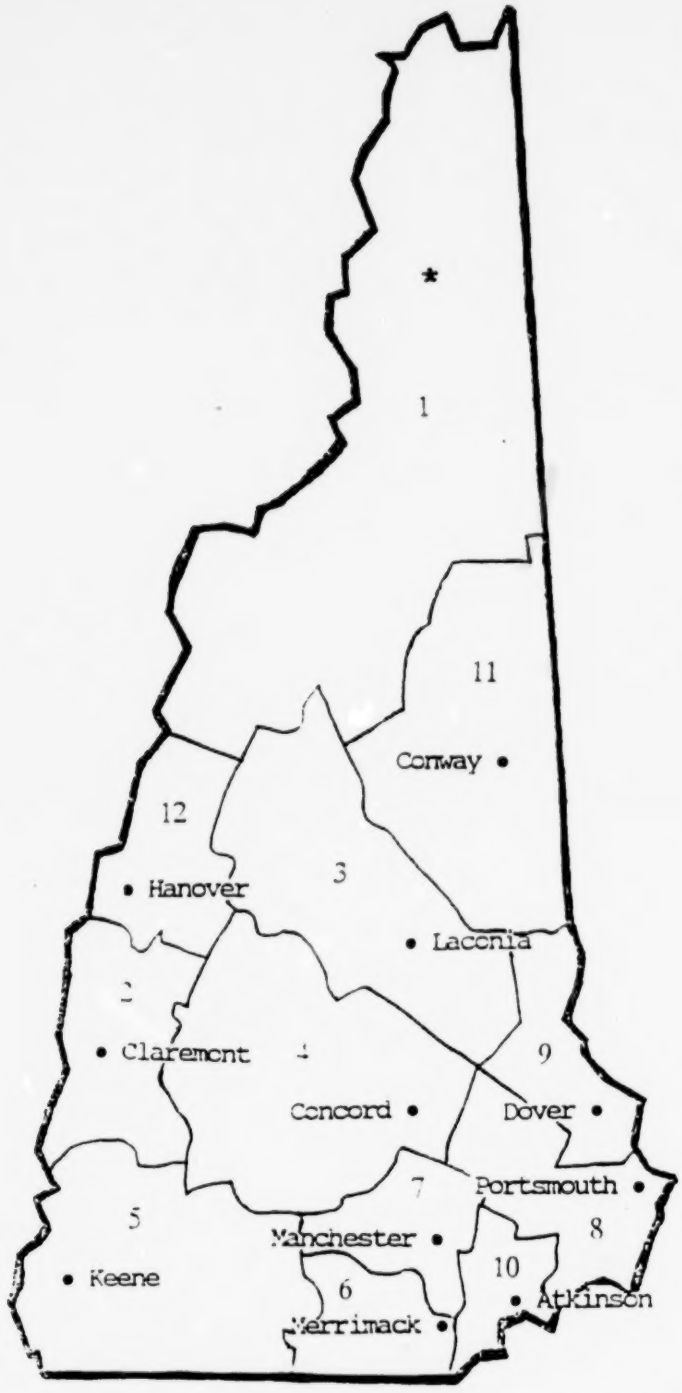
The focus of this study is on two key milestones in the development of the New Hampshire community service system: the concept of the area agencies and the use of the home and community-

based (HCB) Medicaid waiver. Identified as two of the most critical structural features, these have aided the development of the community system in the past decade, facilitating community integration and deinstitutionalization in this state's context.

This case study has three primary sections. It briefly presents an overview and analysis of the regional structures, especially the tension that characterizes the division-region relationship. It describes the home and community-based Medicaid waiver, and contrasts it with intermediate care facilities (ICFs) for people with mental retardation. Finally, the last section presents a framework for thinking about regulations.

Based on semi-structured on-site interviews, this case study is one of many diverse pictures of the development of community services in New Hampshire. It reflects primarily the perspectives of Robert Schultz, a political appointee, George Leskin, a middle manager, and Tom Bradon, the Medicaid waiver manager. This case study is particularly meant to be shared with those working within or with state government in creating positive change in the lives of people with disabilities.

AREA AGENCY REGIONS



REGION 1
Northern NH Mental Health and Developmental Services, Inc.
* See Below

REGION 2
Sullivan County Rehabilitation Center, Claremont

REGION 3
Lakes Region Community Services Council, Laconia

REGION 4
Region IV Area Agency, Concord

REGION 5
Monadnock Developmental Services, Inc., Keene

REGION 6
Area Agency for Developmental Services, Inc., Merrimack

REGION 7
William J. Moore Regional Services, Inc., Manchester

REGION 8
Region VIII Community Development Services Agency, Inc., Portsmouth

REGION 9
Developmental Services of Strafford County, Inc., Dover

REGION 10
Region 10 Community Support Services, Inc., Atkinson

REGION 11
Center of Hope for Developmental Disabilities, Inc., Conway

REGION 12
United Developmental Services, Hanover

* Note: Region 1 main office is located in Conway, part of Region 11.

Reprinted from: New HampshireOffice of Legislative Budget Assistant. (1991, April). State of New Hampshire Developmental Services System Performance Audit. Concord, NH: Author.

AREA AGENCIES

> The area agencies as a milestone event, as a policy construct have been fundamental. I wouldn't change it much at all.
>
> - Robert Schultz

> What I was really interested in, really wanted a commitment to was the concept of area agencies, the concept of private, nonprofit system of providing services external to the state system because I really wanted to see if that could work.
>
> - George Leskin, New Hampshire state administrator

The twelve (12) area agencies are nonprofit corporations designated to provide services for individuals with developmental disabilities in each region of the state. An area agency is the organization which receives funds from the state division for providing services (either directly or through vendors) in areas such as case management, employment, habilitation, family support and residential, and for conducting an internal quality assurance program.

The area agencies were first authorized in law as single entry points in 1979, although none came formally into existence until 1981 when the state division was mandated by the Garrity V. Gallen court order to establish these in accordance with the law (NH Audit report, 1992). All area agencies were operational by 1983.

Each area agency is governed by a Board of Directors and is subject to redesignation by the Division of Mental Health and Developmental Services (DMH/DS) every 4 years. Area agencies are

the regional component of the developmental disabilities services system. State program specialists are the liaisons between the area agencies and the state office, and regular statewide meetings are held in Concord, the state Capitol.

BRIEF HISTORY

The area agencies appear to have been the brainchild of one of the early division directors who believed in the importance of the private, non-profit sector. The concept seemed to have two central aspects: a single, fixed point of referral and the need for a new entity to minimize "warfare between the different competing groups." The area agency concept required an area board with family membership.

While a few area agencies were in existence in early forms prior to the court order, the division was then ordered to develop the rest. The process resulted in a group of citizens being asked if they would be interested in forming a board that would develop services in that region. Action for Independence was the key planning document which guided community development and included the definition of area agencies, program models, planning principles and process, and budgets. Consultants also came in after the litigation to assist in restructuring the community service system through a "systematic and conscientious" planning process which included public forums and intensive interviewing.

Because of the nature of community development during the early years, the area agencies were developed in a fragmented way,

piece by piece as funding and other resources became available. The regional boundaries were determined partially by natural geographic ones, and political compromise, based on the existing relationships between directors. The Developmental Disabilities Act and the dollars that came with it were "really big money" at the time "equal to or greater than the community services budget." As Robert describes how the area agencies came "on line,"

> They had to turn to their communities and put on line a community service system in very fragmented, building block form. You don't have all the pieces you want and you (have) ...to start out...(It is) like going out in the cold with one boot, one sock, a hat, three gloves and a coat because that was what we could fund this year and you really need(ed) more. So they had to...deliver on a very spotty development concept and make it work...They did a great job of it.

From the beginning in the New Hampshire community system, people tried to work together statewide. About 1983, the area agencies and Division came together at the University of New Hampshire and developed a mission statement for the system. Every area agency board adopted the mission statement, though sometimes with changes within it. As one state administrator explained, "it really helped us be really consistent and to measure ourselves and our programs against what our vision of the future was going to be like for people with developmental disabilities."

However, the state officials recognized that creating a system that worked on solely a system basis, without recognition of the people involved, was not possible. As George expressed, "It is the leadership and personalities that make it work the way that it

works." Robert again refers to these ethereal qualities when he describes another major turning point in the state:

> We got a commitment to and a trust of a more integrative life in the service system. And again there were certain individuals who really made that happen, who really saw it, who felt how it could be. And while we saw examples,...there was this turning point...We had come along far enough that we could take the flight of imagination and belief that was required in really seeing what a person's life could be. Things were approximating it enough so that we could start moving towards it...

LOCAL CONTROL: REGIONAL DIFFERENCES AND COMMUNITY TIES

The regional system worked in New Hampshire because it was built upon strong feelings and beliefs within the state regarding local control and the role of state government. As one long time observer and participant shared, "I think in New Hampshire, that idea of local control, that concept or set of feelings around it is actually real."

For New Hampshire, a regional system controlled by the state would not have worked well because there is a strong conservative tendency to resist centralization. "It was very important that local people felt as though it was a local entity that was doing it." A county system also would have been difficult since they "are too small to base the system on."

Local control by the area agencies had two primary features. It resulted in a range of regional differences in how things were done and provided the basis for strong community ties and the capacity to mobilize community support.

Table 1

AREA AGENCY STRUCTURE IN NEW HAMPSHIRE

Local Control

Capacity to Mobilize Community Support

Basis for Strong Community Ties

Regional Differences, Tendency to Resist Centralization

Local Resource Development

Lack of Opposition to Community Development

Greater Flexibility Than State Systems

Resources Not In Competition Between State Contract and Budget Sides

Tension to Monitor the Waiting List

Greater Funding Stability and Flexibility when Combined with Medicaid Waiver

Negotiated Relationship Between State and Local Needs

Each area agency had their own way of doing things, partially dependent on the style of the executive director, the role of the board and families, the communities in the region, and the history of community services development in that area.("They all have a different flavor if you've gone to 3 or 4 of them.") Within the state, other administrators, parents, and disability leaders refer to regions by the first name of the director.

The state office has also encouraged this sense of local control, which results in a variability from region to region on the services operated directly by the area agency and contracted for from other agencies (See Appendix A for examples of three of the state's area agencies). As one long time participant in the service system said,

> As long as they are walking somewhat within the parameters that have been established, there is quite a bit of latitude. So you do see from pillar to post with the area agencies... I think there has been an attempt to try to respect how those things have evolved, while still shaping them, so things are still moving in the direction that people would like.

The area agencies have their roots in the local communities and "they really have pretty successfully managed to mobilize their communities to get community people involved and to be identified with the community." Strategies included inviting the "movers and shakers" of the communities to be on their boards and by "weaving themselves into the political fabric of their community."

From the state perspective, these local ties have numerous advantages, including resource development, overcoming community opposition and meeting the court order, and even protection for the administrators in the central office.

The area agencies held the reponsibility for meeting the goals in the court order and did so often over considerable community opposition. While there were two major cases in Supreme Court on zoning issues, Tom Bradon said, "we haven't had any resistance to a group home or a place where people live since 1986."

The area agencies developed and retained formal and informal relationships with "the town fathers," "the president of the bank" and other community members. These local political ties could also be called upon to assist with issues on the state level.

STATE-AREA AGENCY RELATIONSHIP

Maintaining the tension in the relationship between the state division and the area agencies is credited as being the critical aspect that "makes it work." This tension means that relationships often need to be negotiated, and as one state bureaucrat said, "maybe if you know that everything needs to be negotiated, you act differently." Due to the quasi-public-private nature of the area agencies, they have many of the advantages of close policy implementation that regional authorities offer, and also community ownership of the board of directors.

From a funding perspective, the area agencies were and are

dependent upon the state Division for their resources. ("They were ours, really we owned them. We were their funding source 100% or equivalent of.") Yet, they had to be private, nonprofit and take their own road. As Robert shared:

> They had to have the ability to say to their communities, no I am not the state telling you to do this; I'm the families and the business leaders and the interested parties in here telling you this is what the community needs. So, we had the best of both worlds....This has proven to be an extremely powerful mechanism, powerful legislatively, politically, locally, at the state level, powerful in telling us (the state office) we need to do things differently.

The two major sources of power and control that the state holds in relationship to the area agencies are "the power of the purse" and "quality assurance evaluation activities." This has enabled them to influence both the area agency directors and their boards.

However, state administrators also prefer the area agencies to view the central office as much more than a funding and oversight agency. In addition to traditional power over mechanisms, there is an intent and effort to assist the area agencies to carry out their mission in collaboration with the state office. The state office tries to provide a clear message ("we want community integration") and uses money, regulations, and "nurturing" as a support to the message. As one observer of the system shared, "it is the working relationship that allows for the change."

Maintaining this working relationship requires a constant

investment and a long term commitment since changes do not occur overnight. In many ways, this is the human side of why the area agency structure works. It means an investment in shared responsibility for outcomes in the community and of finding ways of working together through overcoming the human tendencies to blame, to throw one's weight around, or to demand one's own way.

One example of this way of thinking about shared responsibility is in the area of budget problems on the part of an area agency. George Leskin, who worked with the area agencies explained his attitude and approach when this occurred:

> The area agency didn't blow the budget; we blow the budget. We didn't give them enough money; we let them spend money in the wrong places. We don't help them make decisions that are appropriate and we didn't work with the Board to make sure they didn't make the wrong decisions. And then we turn around and say you blew your budget and now we are going to punish you.

Compared to an arms length agreement that is often used to disassociate from providers when problems occur, the management approach here is to recognize that the area agencies are a "part of our organization." This partially stems from a belief that it is simply not helpful to label regions as good or bad.

This attitude is perceived to be mutual when problems occur in the regions. Instead of passing on the problem to the state office and expecting them to resolve it, "we all work on solutions together." Problem solving became the way work was done, not trying to transfer or to fix responsibility as solely that of the region

or the state office.

This does not mean that people do not have their fights (and some are not over), but "we actually never got divorced...because it allowed trust to continue to develop." Yet, a cohesiveness was maintained whereby the area agencies and state government felt they were part of the same effort. As Robert expressed it:

> They are ours and we were theirs, and even though they are private agencies, not state government, that made no difference. And the fact that made no difference is extremely important, that sense of ownership.

It was this sense of ownership, balance and viewing each other as part of the same effort that permeated the decisions and work that occurred.

STRENGTHS AND DISADVANTAGES OF THE SYSTEM

Like any system, the area agency one has a number of disadvantages, many of which seem minor to those involved. These include the lack of control to "order" changes to be done, the determination of eligibility by non-profits, and the monitoring of case management in addition to the issue of regional variability/equity.

Officials from other states really did not believe that this area agency structure design was a good idea. Their concerns were primarily about the loss of control of the waiting list, and the inability to order something to get done as one might with a state

case manager or a state agency. Thus, from a systems management perspective, there were serious flaws that "made them apprehensive about if it would work or not."

Because placements cannot be ordered by the state into the community as it could with Laconia, a constant negotiation process was required. The advantage is that this avoids the problem that occurred with institutions where "state institutions became overwhelmed because when the budget cuts came, the people still had to be placed and the placements occurred and there weren't any people to take care of people and the budgets didn't keep pace."

Yet, this meant placements now needed to be done by problem solving, looking at other resources, "sweetening the pot" and so forth. It required "massaging almost everybody that is at risk, almost on a daily basis" which makes it "a very difficult system to run."

The final concern about the area agency structure was expressed by traditional integrationists as the lack of separation of case management from services in some area agencies. This means, in this perspective, that there is a lack of oversight and monitoring of services that would otherwise be solved, at least in part, by this separation. Yet, when leadership has been consistent and commitment is significant, this may not be perceived as much as an issue.

The area agency structure also has at least four other advantages from the state viewpoint: greater flexibility than state

systems, resources not in competition between state and contract budget sides, tension to monitor the waiting list, and greater funding stability and flexibility when combined with the Medicaid waiver.

As changes occur in the field, it is critical that the state system have an ability to respond to what has been learned. However, as a general rule, George Leskin said, "state systems always seem to me to be relatively inflexible, and relatively unable to respond to changes that occur in the field." The area agency structure, in contrast, has greater flexibility.

Second, when budget reductions occur, the tendency is to always reduce the contract side in order to maintain the funding in state employee resources. By setting up a system that does not place the private community sector in competition with the state community sector, this type of biased competition for resources is reduced.

The area agency structure also sets up a tension between state and local levels that helps to monitor the waiting list and does not allow the system to deteriorate. In essence, this is a version of the governmental checks and balances with the area agencies moving the state along ("We've learned a lot of things. They keep us moving. They help prod us along.") at the same time the state forwards its own interests with the area agencies.

Finally, when merged with the home and community-based Medicaid waiver, it becomes a powerful system to be flexible,

creative, and yet foster stability of financial resources. As one state official said,

> I am absolutely confident that our system will be a better system over time in face of any future budget cuts than the alternative system or the older system.

THE FUTURE

Throughout the past decade, the area agency structure has proved to be a viable mechanism in New Hampshire contributing a structure that did not stand in the way of the ongoing changes in philosophy and service delivery that occurred. Now that the family support councils are in place in each region and the state Division's constituency is starting to shift away from the area agencies and their boards toward family members, the future for the area agencies is unknown. As an observer shared about the changes that are now but glimpses of the future:

> We aren't sure what will come after it because your constituency is evolving away from area agencies and their boards; (at some point) they are going to be looked at as nothing more than bureaucrats at the local level.

While the area agency structure has had the flexibility to meet the needs of the past, the questions of the future remain to be seen as families may have more control over the directions yet to come.

HOME AND COMMUNITY-BASED MEDICAID WAIVER

> I think the two real critical pieces of developing communities, one was the area agency and the other was the community care waiver. Neither one of those really worked well without the other.

BRIEF OVERVIEW: NEW HAMPSHIRE MEDICAID WAIVER

Simply stated, there would not be a community service system in New Hampshire without the home and community-based Medicaid waiver. Medicaid at the time of the site visits funded $55 million of the total system with $47-48 million waiver money for services for individuals. This represented about 60% of the total revenues in the system, including state and federal funds, client fees and other items. The federal share was 50% with 50% state share.

The New Hampshire waiver basically funded three kinds of services: residential or personal care, day habilitation (includes adult day activities and support of client) and case management services. The rate structure was five tiered with the range being from $35 to $191 a day with three rates in between. Rates are prior authorized based on a combination of the needs of the people and the way the services are organized because

> the most handicapped are not necessarily the most expensive per se. It has as much to do with the way services are organized as anything else.

According to the informants, compared to other states, more of New Hampshire's services are bundled under the waiver which DMH-DS

manages than in the state Medicaid plan. The state also planned in 1992 to add some services which were common in other waivers - respite, family support and architectural modifications - and which were previously paid for only through state funds.

The area agencies are the only designated providers of waiver services in their region. Everything is coordinated through the regional agency whether from a program or a client basis, which as Tom underlined, is "real important." The specifics around documentation and about what people need to do is more consistent if it's run through a single agency. The area agencies and state office share values "that we're all collectively trying to work toward" even though people may be at various stages along the way. Every year was viewed as a new challenge that cannot always be predicted.

As Tom Bradon described, the ongoing "partnership" with Medicaid in Boston has been a real strength, especially "their willingness to talk with us, to listen to what it is we want to do, and their willingness to kind of allow us to do what makes sense for the people served in the system." This communication flow is critical because formal amendments are made in the waiver almost every year to reflect changes in the costs or ways that services are provided in New Hampshire.

One of the greatest strengths of the Medicaid waiver program is that it is flexible enough to change as services, philosophy and other developments have occurred in the field. As George, a very

strong proponent of the waiver, stressed:

> The issue of the waiver is really important because what the Medicaid waiver really is it's a waiver of the ICF-MR Medicaid rules and regulations. And so without the waiver, we don't have the flexibility to put together the system of options in a variety of different ways...It is very important that we continue to keep the concept of a Medicaid waiver.

The waiver, for example, was and is flexible enough to allow for homes of any size to be set up, and over the years this has meant more homes for one, two or three people. Thus, as the thinking of people in agencies has changed, the waiver has been able to be adapted. For example,

> Many agencies that operate 8-bed models that we used to run are breaking those up or have broken those up and now have eight one person placements...And they're no longer thinking of people as a group.

This is considered to be a positive development since it accommodates more individual lifestyles, promotes more natural rhythms of the family, more flexibility for the person, and more choice in what to do and the type of residential program (where people live). As the Medicaid waiver liaison stated,

> People live in families, people live with roommates, people live by themselves with support brought in as needed. They may live with friends, friends who may have a disability or not. Some people live in (homes of) four (or) six; we do have some eight-bed residences still. People live in apartments, condos, townhouses, homes, all kinds of places.

The waiver also has, from at least the mid '80s, served people with "characteristics similar to people at Laconia or New Hampshire

State Hospital." It thus seems to provide sufficient support and flexibility for service providers to serve anybody at any level in the community. The waiver served three major functions: providing money for early experiences with people with severe disabilities, core funding for the community service system development, and a mechanism to transfer money out of the institution into the community. As one person explained, the waiver was "critical by the way, absolutely critical in closing Laconia (the state institution). I mean, they couldn't have done it without it."

One state administrator reported that a "lot of people do not like our waiver, but it has been a good waiver for us." The major limitation of the waiver to date, from the perspective of the state office, has been the restrictions placed on paying for supported employment for those who were not previously institutionalized.

Most of the other perceived weaknesses come from adapting to changes that occur within the state in service provision. For example, the state office in 1992 submitted an amendment to increase the number of reserve bed days allowable so that people could spend more time at home with their families if they desired to do so.

The waiver was renewed for another five year period and the major challenge from this state perspective is to generate the state match for the federal funds. Over the next five years, the Medicaid federal share will increase to $82 million. With this renewal, "For the first time, we can pay family members to provide

supports in the home. It is a big step in rethinking what our entitlement ought to be to...be for." In part, because of the waiver renewal, which "to us was really life and death," New Hampshire did not apply for the Community Supported Living Arrangements instead using their state match money for the waiver.

INTERMEDIATE CARE FACILITIES (ICFs) IN NEW HAMPSHIRE

New Hampshire never invested greatly in the ICF-MR program compared to other states. In 1992, there were 58 ICF-MR beds in New Hampshire at seven different locations representing a total of $4 and a half million. The certificate of need process for ICF-MRs and nursing homes has always been subject to the local planning process. Any new ICF-MRs are controlled, regulated and authorized by the division through the commissioner's office. This means that "private providers elsewhere could not just come in and set up business and operate in the future. It just isn't allowed."

In the mid-1980s, there was "serious long term planning" regarding the medical management facility in Hanover. It was an effort to serve people with the most severe medical needs who were institutionalized. Around 1986 there were three units built, one a 10-bed for people with severe medical disabilities near Dartmouth Medical School (reduced from the original plan of 24), and two 6-bed ICF-MRs for people with challenging behaviors. Within two years, the private provider decided there's "no inherent benefit", "no economy of scale at all" and "no grouping of expert behavior

services that makes this any better than anywhere else." It is also "exceedingly expensive."

In New Hampshire, providers are moving away from even the few ICF-MRs that are now in operation. In fact, several agencies are looking at alternatives in the community even though this may mean a reduction in the total gross dollars that they would receive. The stated reason is because they basically believe this is in the person's best interest. For example, as Tom Brandon described:

> Another ICF-MR that was HUD (Housing and Urban Development) funded about 10 years ago, and served people with severe medical issues, who were all non-ambulatory, required total care, they basically found that they could serve individuals much better by placing them with staff members into the community in the staff member's home, modifying the homes, giving them small lift vans or providing that accessibility.

There is still a pediatric facility for children in the southwestern part of the state. This enrolled Medicaid provider was started inthe 1950s by families and is not under contract with the state Division. As family supports have increased to keep children at home, the provider started marketing region-wide in the Northeast. The area agency has been working to try to show families different choices of where children can live.

> And last year one of the kids...had been living there for 10 years, came home and lived with a supportive foster family. And after six months (the child) is now moved back with her natural family, where the child hasn't been for 11 years. And the family's doing remarkably well. And the child is just blossoming and is back in public schools.

New Hampshire has continued to adapt their financing to match their

goals for community life for families and their children with disabilities.

COMPARING WAIVERS AND ICF-MRs

According to one administrator, the waiver is "not as good a funding stream as ICF-MR because you have cost reimbursement under the ICF-MR and you don't have that under the waiver." While ICF-MR funding is more dependable from the perspective of the provider of service, it is less cost-effective than the Medicaid waiver. Basically, according to one administrator, with ICFs, the provider has a basic budget for the year which does not vary based on the actual number of people. As he explains:

> In the old days, and in the ICFs still, you don't operate like you are running a business. You perform a service and you, particularly in state ICF-MRs, you have a budget set aside and you just draw it down. So it never really matters to you, as an institution, whether you have a 100 people or you have 50. Because you have a budget for a 100 and you happen to wind up with 75, well too bad, or maybe our billing to Medicaid next year is only going to be for 75, but the basic budget is the same.

With the New Hampshire Medicaid waiver, services are provided for the agreed upon amount which is cost effective. Also, the rates can vary by individual, while in the institution, there was the same rate for each person. A state official shared the following example:

> My friend Ray...(has moved) and has gone into his own apartment with some little supports and he is very comfortable and happy doing that. But when he was at Laconia his rate was

like $200 a day, and his rate in the community now is probably $20-25 a day.

It was not until the waiver was approved and being implemented that "we began to see how important it was to have area agencies." Area agencies provide services and they are reimbursed by Medicaid after they perform the service. Because of how the system works, at times Medicaid checks do not come in and an organization must have the capacity to borrow money.

The state itself did not have the capacity to operate in this way, which is very different than how institutional services were funded. The area agencies were in the position where they needed to carry funding, or have an agency line of credit as part of the regular process. This was not easy for a state agency to do in response to ongoing changes. So the area agencies provide the capacity within the system to make it work that the state agency alone could not do. As one state administrator explained the importance of being able to do business as other businesses do,

> In fact, time to time, Medicaid checks don't come in, so the agency goes to the bank and pays their bills and then the Medicaid checks come in and they pay off their line of credit. Try doing that with a state agency; I've worked for the state many, many years. That's a total impossibility, you can't respond to changes as they occur...The capacity to be flexible and to do what other businesses do...is really important in a community services system.

MEDICAID AND ACTIVE TREATMENT

Although there are certain standards that states must meet for waivers, such as health and safety, within those parameters the

state has flexibility "to put together programs in ways that are appropriate to the individual." The waivers are not as oriented toward deficits, active treatment, and therapeutic services as the ICF-MR model. It thus allows greater ability to focus on capacities and to help the individual develop his competencies living in the community.

The Medicaid "ICF-MR" concept of active treatment has proved to be an impediment and has carried over into other community programs, including areas such as Part H. Active treatment presumes a "deficiency view of the individual" and "keeps you focused on the dependency and the deficits rather than...the capacities."

One state administrator explained, in a study of people who left or stayed at Laconia State School conducted in 1985, "we were able to demonstrate for severely disabled people in a matched comparison sample" that the people "on the community side...gained more in their adaptive skills and gained a better capacity in their maladaptive skills than the active treatment side." In other words, even if people received less occupational, physical and speech therapy (the foundations of active treatment) than their counterparts, and instead participated in supported employment, reasonable living situations and recreation, they gained in their adaptive behaviors and decreased in maladaptive ones.

Active treatment also is tied closely with the old "train and place" model of services and becomes an end in itself ("we provide the treatment and the individual gets lost in the process.") This

administrator continued, if you place the person then "do what you need to do, it is only rarely something to do with therapies, and it is more to helping people adjust, getting them the support, helping employers." He shared this story about a young man who had been both at Laconia and at a mental health hospital:

> He's still at Bonanza. He still works there. On an active treatment basis, we never would have been able to work with him. I mean, we would have treated him; we would have tried to cure him. And we would have tried to make sure his behaviors were appropriate before we took him to Bonanza, and he never would have made it.

Active treatment has also added to the escalating costs of Medicaid, partially because it is both a subjective and a volatile issue.

> So they (the surveyors) constantly keep pushing you up the active treatment hierarchy scale, hire more staff, do more pt, do more this, for which they are willing to pay the federal share and you have to pay the match. I mean the reason that institutions now cost $300, $400, $500 a day, is simply because of the concept of active treatment.

One professional shared an example of the way that costs escalate by the requirements for active treatment, particularly as it relates to the cost of professionals. Instead of helping someone with her toothbrushing, if positive reinforcement was given, thus defining it as a behavioral treatment program then this could be supervised by a licensed psychologist under active treatment guidelines. One of the reasons "the waiver was such a Godsend" was because it moved away from this emphasis on active treatment and

trying to cure people.

> I'm not saying that active treatment isn't something that some... (people) ought to have, but in a business of developmental disabilities where people aren't sick to begin with, it escapes me why we spend so much on active treatment.... (and) very little going to the kinds of things that enhance people's ability to live.

The Medicaid waivers represent, in some ways, a concrete step toward the direction of reform of Medicaid. As one state administrator shared, his major concerns about Medicaid are the increasing expense and restrictiveness. He views the Medicaid "waivers" as a way to address both of these concerns and believes that the solutions to long term care are in the waiver process. He explained,

> I believe...I could still do a better job than I am doing now, if I had less restrictions about the way to put services together. Not all those restrictions are Medicaid restrictions; some of them are our own (state) need to make sure that people are protected from risk almost beyond the point that it is reasonable, simply because they get Medicaid money.

REGULATIONS: THE FEDERAL-STATE ROLES

> I think that the answer to Medicaid expenditures is to continue to move in the direction of individualization, of local and family community supports, and of reducing the unnecessary restrictions around fire safety codes, other kinds of codes.

The insights and observations in this section are particularly based on the perspectives of one state administrator who has had a major role regarding the development of regulations in the community system. While not necessarily reflective in specifics of other views, his general attitude of less regulation by government is characteristic of New Hampshire and offers some lessons in thinking about a few of the central issues regarding the role of regulations and the federal-state-regional-person relationships.

THE FEDERAL APPROACH: THE SEARCH FOR A NO RISK APPROACH TO LIFE

The basic approach to regulation on the federal level, particularly with Medicaid, has tended to be to control risk through regulations. While the intent is laudable, the effect on human life can be that requirements and regulations take away the everyday risks of human living and that more money is spent on issues that do not substantively improve the life quality of people with disabilities. One effect of regulations is that the person can end up being viewed in a less valued way than others because of the restrictions to their way of life.

Legislators and bureaucrats try to eliminate all risk from

Table 2

TWO APPROACHES TO REGULATIONS

Standard Approach To Regulations

Purpose: To control risk through legislation.

Assumptions:

Presumes best solutions can be determined far ahead and without intimate knowledge of potential solutions.

Based upon prohibiting certain behaviors and actions.

Effects:

- Money can be spent without substantial improvement in life quality.
- Person can become viewed as less valued than other citizens.
- Limitations on opportunities in order to avoid agency/program risk.
- Decreased provider flexibility.
- Best parts of living are taken away: excitement, uniqueness, meaning.
- Erosion of systems creativity; increase in bureaucracy.

Other Factors Supporting Regulatory Framework:

Personal interests of employees in ICF-MRs.

Legislative and fire marshall tendencies toward risk reduction.

Desire for consistency.

Desire for precise definition of problems and proposed solutions.

Desire to prevent wrongdoing.

Another Approach to Addressing Risk and Safety

Purpose: Facilitate problem solving at the community and fmaily levels.

Assumptions:

Presumes that people are basically good and want, are willing and have the capacity to do the "right thing."

Based on facilitating positive actions, individuation, and quality life conditions.

Nature of human life involves risk taking.

Effort is to target change in the real problems in community life, with responses such as changes in outmoded service patterns.

Effects:

- Reduction of unneccessary restrictions around codes which often cost money without quality of life effect.
- Assuring safety through relationships.
- Apply the same, not higher standards to people with disabilities.
- Avoids standardization and pushing decisions up the hierarchy.
- Does not preclude use of regulations.

Other Factors Supporting Framework:

Local control and development

Rapidly changing nature of disability field.

Existing standards and programs always jumping beyond standards as they are written. That process alone makes the individual that participates in those programs less than (s)he could be in human terms. In other words, the elimination of risk eliminates the vitality of opportunities.

The major argument this administrator suggests is that everyone takes risks on a daily basis and that this represents the very nature of what human life is about. By trying to legislate away risks, some of the best parts of living are also taken away from people with disabilities, robbing them of excitement, uniqueness, and meaningful personal experiences.

> And by legislating out risk, so you can't live in a building that has a wood stove,...smell the burning (firewood or)...feel the energy from bringing in the wood...All those kinds of things that we do to try to help people, wind up taking away from the kind of exquisiteness that can be involved in living your life.

Another problem with the tendency to use regulations as the primary mechanism to assure or promote quality is their cost. Money is spent primarily on meeting the rules and standards, without necessarily any benefit to the people with disabilities involved in the programs, but with increased costs to the taxpayers. Sometimes the costs become so great that programs fall of their own weight, which can actually be to the benefit of people with disabilities.

> They try to write in so many protections for a very limited amount of money that the cost of the protections eats up the money that states agree to participate...clearly we got to the point with the ICF-MRs that it wasn't worth it. They had so many rules and regulations that it wasn't worth participating anymore, which is probably the best thing that ever happened to mentally retarded folks. So now they won't have to go to institutions.

According to this state administrator, regulations result in

increased resources placed into monitoring and this rule development starts a cycle whereby creativity is slowly eroded within the systems and more and more regulatory bureaucracy develops. It is his view that regulations should help develop community norms, but not control from the state level.

> The next thing that happens is you have to have people go out and check these regulations and then you get so many standards and so many things that you can't meet them all. And then everybody is in violation of the regulations. Then you call the money back because they don't meet the regulatory standards. It is insidious the way it destroys the creativity of people who actually can figure out most of it themselves if they are given the opportunity.

More importantly, in this framework, regulations are considered basically a misdirected response to the problems of quality in community life. Instead of placing more specific requirements and increasing costs, sometimes other fundamental changes are necessary such as moving away from outmoded service delivery patterns such as nursing homes.

> The issue is not how to straighten the nursing homes out by putting more regulations on nursing homes. What we should do is stop sending people to nursing homes, provide supports in their homes and their families and support for them...We pay more and more money for more professionalized services in environments that don't help people.

THE STATE APPROACH: SAFETY OR DISCRIMINATION?

This same approach to risk also occurs on the state level and it is considered to be an almost overwhelming, day-to-day struggle to keep the bureaucracy out of the lives of people with disabilities.

A 1991 example was occurring in New Hampshire around the issue of life safety codes. In 1990, a state law was passed that basically said if a person with a disability was going to rent an apartment, that apartment should meet the same lifesafety codes as any individual, single family dwelling in the community so a person could live wherever anyone else could.

Yet, the local fire marshall in one region was insisting that any certified home must be sprinkled, even if the person with a disaiblity would be living there with a personal attendant. This meant that the home had to have restrictions that immediately pointed people with disabilities out as different from the landlord and the neighbors. In other words, the person was "not allowed the same risk that any other person moving into that apartment could have." The fire marshall, acting diligently in accord with his beliefs, wrote a letter to the state administrator's commissioner saying "we are endangering the lives of people for whom we are responsible."

The primary question seems to be whether people with disabilities, by virtue of their disability or by receiving state and federal funds, should be required to live in more restricted/safeguarded environments or if such actions are a form of discrimination, holding people with disabilities to higher standards than the rest of the population.

> I think they (federal and state fire officials) are making significant inroads in trying to have every person with a

> developmental disability or mental illness or aging live in a fully sprinkled, dual access environment. And they don't just do that for everybody. They, I think, are discriminating against people with developmental disabilities and requiring them to meet higher standards in order to live in integrated settings in our communities.

In addition, there is a fear that as the power of the fire marshalls increases people with disabilities will be forced back into rigid institutionalized environments, which will become the only ones that can easily meet their standards.

Like other issues of discrimination, the stated reasons or debate do not revolve around these distinctions, instead being framed in terms of the safety of these individuals. When combined with the legislative tendency toward risk reduction and the personal interests of employees in ICF-MR settings, this is a potentially large threat to moving toward more "individuation" and back to institutionalization.

> And what better group of people to get together to fight any individualized future for folks than those three powerful groups. So I think it's real challenge.

WAYS OF THINKING ABOUT STANDARDS

Another way to think about standards and regulations proposed by this administrator is to use a similar philosophy and approach to that taken with families. His basic assumption is that a family is or has the potential to be a good and loving family. When this positive framework is applied to providers, then the emphasis is toward less, not more regulation, with an emphasis on working with

good intentions to create better quality conditions. Standards thus serve the function of facilitating problem solving at the community and family level instead of dictating solutions through the application of rules.

> I chose to believe that every family can become or will become, or has the potential to become a loving, caregiving family. So I always start with the assumption that people that we have in our programs, working with our programs, are not doing this simply to get rich. Yes, there is a certain amount of monitoring that is necessary, but my belief is that less regulations (are) better than more, and less standards are better than more.

The issue of regulation is not disability-specific and cuts across all areas of life wherever abuse or perceived abuse can take place. Particularly when an evident injustice has occurred, the tendency is to create a standard to try to stop it from happening again. It is important to develop a belief that people can be assured safety more by relationships than by regulations.

Regulations also presume that the best solutions can be determined far ahead along the road and without an intimate knowledge of the particular situations. The more complex and changeable these issues become, such as the nature of human lives, the less this assumption may hold true.

> Another thing..we can never figure things out for people with disabilities this far in advance and this far from the problem. I think one of the things we have been successful with and one of the reasons our programs have been able to change and keep up with all of the new technology is that we have the flexibility to do that.

Regulations also tend to focus on prohibiting certain

behaviors or actions when what is often necessary is to facilitate positive actions, allowing people to "do the right thing." This perspective is based on the belief that people at the operational level have the capacity and willingness to "do the right thing" with support.

> But I basically believe in the capacity of individuals to do the right thing. And I think, it is pollyanish, but people aren't inherently bad, and I think we have to facilitate their capacity to do the right thing rather than prohibit their ability to do the wrong thing.

There are two major forces that constantly push states, federal agencies and localities toward increased regulations: the desire for consistency from area to area and the desire for accurate and precise definition of problems and proposed solutions.

The opposite side of the coin of flexibility is that differences may exist from area to area. This equity issue can be of great concern, for example, to a family who may move from one region to another, and does not have access to the same options in another area.

> It generates a considerable amount of criticism (from) people who move from here and can't get it over here...same state, same regulations, but different ways of doing things...this is an ongoing battle...to not over regulate the way in which providers or programs can have the flexibility to deal with issues.

The New Hampshire state legislature also tends to demand greater specificity, which not only limits flexibility, but also increases the work of bureaucracies, using resources toward these

administrative ends. In many ways, equity may lead to more regulation and to reduced flexibility on the part of the providers.

One example of an effort to move away from rigid standards was in the area of family suppport. When they were first written, it was clear that they were "too regulatory," "too controlling," "not family enough" and not "user friendly." So once circulated, they were rewritten in simple language, but then the state office received pressure "because they didn't have enough body to them; and too much decisionmaking was placed on the part of the family support councils instead of telling them what they needed to do."

The issue of outdated standards is also a constant problem that is practically inherent within any rapidly changing field. As he explains, "the...(quality assurance) people are out there trying to regulate the programs on the (existing) standards and our programs jump beyond the standards all the time. As soon as we write a standard, we realize that they are not appropriate anymore. Our standards for residential placement are...(not) near what we are doing with... individual placement options."

This administrator called fighting bureaucracies an ongoing battle that must be fought with vigilance on a daily basis. The tendency is toward standardization and toward pushing decisions up the hierarchy.

> So that is one thing we continue to fight against is over regulation at the central office level and to leave decisionmaking to the lower level of the people who are actually doing the work, who know what needs to be done. We've done an adequate job of holding our own, but the press

of bureaucracy to make cookie cutters out of programs is overwhelming...You simply have to fight it everyday.

He assesses their efforts in New Hampshire on this as successful, although it is a continuous problem here as in other states.

And so far, we have been very successful, and it is an ongoing battle, and I think a major, major battle that needs to be fought in ...(every) state. So we have really done okay. We have not done as well as I would like, but we're continuing to fight the battle.

CONCLUSION

These New Hampshire state administrators have a number of lessons to share from their extensive experience in developing a community service system from its fledgling beginnings a decade ago. These include:

- the importance of local control, the development of a sense of community ownership and the mobilization of community resources;
- the role that intermediary structures play in allowing the necessary flexibility to meet individual circumstances;
- the need for a changing role of government as the role of family members increases;
- the flexibility and cost-effectiveness of the Medicaid waiver in moving from institutional to community life;
- the continuing programmatic and cost issues with the implementation of the outdated concept of active treatment;
- the role of negotiation, collaboration and checks and balances between state and regional levels; and
- the effect of regulations on the life quality of individuals with disabilities and on the use of limited resources.

Whether examined from a structural, philosophical, practical or a personal perspective, New Hampshire's experiences form a base for comparative discussion in other states which face similar issues.

APPENDIX A

Monadnock Developmental Services

Region VI, New Hampshire

Developmental Services of Strafford Co., Inc.

Table 3

Monadnock Developmental Services

Region V, New Hampshire

This region was visited because it was described as having the best examples of supported employment in the state of New Hampshire, serving for example, in 1986 as one of the area agencies selected for the development of community employment. The case study report of the region [1], which served about 350 people with a $6.5 million budget in the southwestern part of the state, highlighted the following factors associated with the change process toward integrated employment:

* Workshop closure. As of summer 1992, the region had disbanded their two sheltered workshops.

* RFP process. All community service providers needed to submit proposals and interview in order to obtain contracts, resulting in thre provider defunded and five remaining providers in the region.

* Performance review and quality assurance. Developed jointly with the area agency, these are reviewed by outside consultant three or four times a year.

* Money tied to people. Interpreted as a fee-for-service system whereby day and residential service agencies will only be paid for units of services provided.

* Person-centered planning and individualized job placement. Each of the three agencies visited described a commitment to "individualized job placements" and center planning around "getting to know the person and learning about their dreams."

* Natural supports. All agencies said they had an orientation toward natural supports, which was described as the term used to mean "support provided by job site personnel and/or other non-human service people."

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[1] For the case study report on this region, see Rogan, P. (1993, January). Integrated employment for all. (NARIC document, 8455 Colesville Rd., Suite 935, Silver Springs, MD 02194).

Table 3 continued
Monadnock Developmental Services

* School-to-work transition. Described as relatively new for school and adult agencies to work together to facilitate movement of students from school to postschool work and living.

* Providing only work related supports versus other support. Emphasis was to keep the focus on employment, including marketing, though two agencies were required to serve people six hours a day.

Table 4

Deinstitutionalization to Support
Region VI, New Hampshire

This region was nominated for study because it was considered to be one of the strongest in the state, especially in relationship to case management, family support services, and quality assurance.[2] Region VI encompasses the cities of Nashua and Merrimack, and in 1991 served 400 people with a budget of $9 million. According to the case study report, the following are examples of key regional practices:

Case management.

* Use of "action plans" instead of standard use of the ISP meeting for people who dislike to use this process.

* Use of beeper for case management availability and efforts to develop back up supports with vendor organizations.

* Use of an advocacy orientation for people with disabilities by case managers in instances of disagreement of conflict with vendors and/or the person's parents.

* Redefinition of the job as a benefits technician.

* Assisting people who have developmental disabilities and mental health lables residing in mental health institutions.

Family support services.

* Approximately 200 families receiving family support with no waiting list.

* Use of family support advisory council, family liaison, recreational links, parent-to-parent program and respite.

* Approximatley 90 children in out-of-district placements in residential facilities or schools, targeted to be brought back home.

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[2]For the case study report on the region, see Walker, P.(1993, March), Coming home: From deinstitutionalization to supporting people in their own homes in Region VI, New Hampshire (also available from NARIC).

Table 4 continued
Region VI, New Hampshire

Development of individualized supports.
* Options being pursued for people with "severe" disabilities include
- assisting people to rent or purchase a house and live with nonpaid roommates and additonal staff support;
- assisting people to live "on their own", in a rented or purchased house, with drop-in staff support;
- assisting people to share someone else's home.

* Decrease in amount of property owned by the area agency; change in expectations of vendor agencies.

* Assisting people to make choices about where they want to live and with whom.

* Financing of home ownership and regular use of Section 8.

* Planning with families to develop options, including taking on the roles of vendor and casemanager.

Quality assurance.
* Based on the "five accomplishments" drawn from the normalization principles--(1) community presence; (2) protection of rights and promotion of personal interests; (3) competence development; (4) status improvemnt; and (5) community participation.

Table 5

Regional Support System
Dover, New Hampshire

This agency was nominated specifically for its practices for supporting adults to live in the community.[3] Founded in 1982, the agency supported 180 people with developmental disabilities including (as of 1991) 60 people supported through the agency's residential services, 55 of whom were living in "their own place."

The agency's agenda is to support the "same kind of valuable things in the lives of people with disabilities--friends, family, home and work--as all of us want." This agency strives to expand the network of community places and relationships in the lives of the people it supports.

This agency was examining ways to reorganize their resources--people, services, finances--to figure out how to determine and to provide the support that people want or to assist people to develop the connections or relationships where such support will occur. The case study describes the following examples of significant issues:

Community places and relationships
* Staff roles and strategies in supporting the process, both good and bad, of connecting in the community.
* Learning to value each other's contributions besides those based on standard concepts of productivity and performance.
* Knowing what it means to live together and how in practice this contributes to a vision of coexistence.

"Supporting" what is people want
* Getting to know and trust each other, including the process of feeling safe and accepted for who people are.
* Instilling flexibility into agencies.
* The human process of making mistakes and the importance of recognizing when something is not working.

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[3] The case study on this agency, "People want the same things we all do:" The story of the area agency in Dover, New Hampshire, can be obtained from Community and Policy Studies, 2103 S. Geddes Street, Syracuse, New York.

Table 5
Regional Support System

Personal choice, self-advocacy and families

* Distinguishing the views of parents from adults with disabilities.
* Personal choice as a part of everyday living, and self-advocacy as "people collectively standing up and expressing a point of view."

Ways of organizing to provide support

* Commitment of staff to a core set of values.
* Changing the information and decisionmaking processes among the staff.
* Personal relationships between staff and people with disabilities, including using personal networks.
* Attention to what it is direct service staff want and need.
* Paid roommates, neighbors and staff roles, and the question "Whose home is it?"
* Exploring safeguards in an agency with an internal case management structure.
* Cost-effectiveness of supporting people to live in "their own place."
* Liaison role with the state office on financing and information.

Community Integration and Deinstitutionalization in New Hampshire

1993/94

Also available:

Characteristics, practices and comparative roles in the change process

Garrity V. Gallen: The role of the courts in institutional closure

The closing of Laconia: From the inside out

A qualitative study of self advocacy and guardianship: Views from New Hampshire

"People want the same things we all do': The story of the area agency in Dover, New Hamsphire

Available from:

Community and Policy Studies
2103 S. Geddes Street
P.O. Box 184
Syracuse, New York 13207